

**Pain, Aching, Stiffness and Swelling
Growing and Sustaining State Arthritis Programs:
Results of a Systematic Review of State Arthritis Programs
Funded by the CDC 1999-2005**

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**Pain, Aching, Stiffness and Swelling
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Results of a Systematic Review of
State Arthritis Programs funded by CDC 1999-2005**

Background: Following the development and publication of the *National Arthritis Action Plan: a Public Health Strategy* CDC received a Congressional appropriation (1999) most of which was used to support arthritis program capacity building, program planning, and implementation in state health departments.

Currently, states are funded under consolidated Program Announcement (PA) 03022--Chronic Disease Prevention and Health Promotion Programs. PA 03022 specifically supports cooperative agreement funding for seven program components: 1) Tobacco; 2) Nutrition, Physical Activity, Obesity; 3) WiseWoman; 4) Oral Disease; 5) BRFSS; 6) Genomics; and 7) Arthritis. Thirty six states receive cooperative agreement funding to support the Arthritis component of PA 03022.

In 2005, the Arthritis Council, National Association of Chronic Disease Directors (CDD), initiated a systematic review to build on previous work done to assess state arthritis program capacity since CDC cooperative agreement funding was initiated in late 1999.

Purpose: The purpose of the project was to review the progress of State Arthritis Programs (from 1999-2005) by gathering information on the successes and challenges experienced by these programs; to extract lessons learned; and to identify facilitators and barriers to success. This information will be useful to increase efficiency and our ability to reach people affected by arthritis.

State Program Activities:

Twenty-eight states currently receive Capacity Building Level A funds (average \$140,000/year). Level A recipients were asked to:

- Support a full time arthritis program manager;
- Establish and maintain an advisory group or coalition;
- Conduct surveillance using the BRFSS and make the data widely available;
- Develop a state plan for arthritis;
- Implement and measure the reach of one or more evidence based self management interventions.

Eight states receive Capacity Building Level B funds (average \$250,000/year). Level B recipients were asked to:

- Implementing all Level A activities;
- Implement and measure the reach of two or more evidence based self management interventions on a broader basis than level A funded states.

Program direction became more specific after 2000: CDC recommended the implementation of three evidenced-based programs (Arthritis Foundation Self Help Program, Arthritis Foundation Exercise Program, and the Arthritis Foundation Aquatic

Program). When the health communications campaign became available in 2000, this was also added to the list of evidence-based interventions.

States were viewed as successful if they accomplished the activities as outlined above. Based on the information obtained in the site visits, the program announcement, and program guidance given to states, we provide a definition of success for eight of ten components reviewed. Since awareness and policy activities were not addressed in the program announcement and no guidance has been given around these two components, a definition of success is not given for them.

Process/Methods: A standard protocol was developed to address overall program status and ten component-specific activities (funding, program operations and staffing, surveillance, advisory group, partnerships, state plan, interventions, program evaluation, public awareness and education, and policy development.). A team of three reviewers conducted fifteen two-day site visits between January 24 and November 10, 2005. The review team included a CDD Consultant who led all 15 visits, a CDC Arthritis Program Project Officer, and a CDC Arthritis Program Scientist. See Appendices 1 and 2 for a detailed description of the protocol and the protocol forms. See Appendix 3 for a list of states visited.

A retreat was held November 30 through December 2, 2005 to review the findings from the 15 site visits, identify major overall themes, define success in the ten cooperative agreement subcomponents, and look for common facilitators and barriers for success or lack thereof. Proposed solutions were also identified, based on suggestions from the states and the retreat committee. See Appendix 4 for a list of people participating in the retreat.

Results:

Overall impressions/observations:

The positive:

1. There are currently 36 state arthritis programs working to improve the quality of life for persons with arthritis. There were only two (Missouri and Ohio) in 1998.
2. Because of state arthritis program activities, money was appropriated by state legislatures in several instances. The funds did not necessarily go to support the state arthritis program, however.
3. States have data available about arthritis and data have been disseminated to partners, policy makers, and the public.
4. Although still limited, arthritis is more visible as a public health problem than in 1999.
5. The availability of evidence-based interventions has improved.
6. The states and CDC have actively pursued and applied lessons learned and are willing to work together to modify program goals and how they are achieved.

Specifically:

- Setting goals and objectives for CDC and state arthritis programs.
- Identifying infrastructure needs for evidence-based programs and how to meet them.
- Clarifying roles between CDC and states, and states and their partners.
- Improving communication.

- Developing defensible, practical surveillance.

The challenges:

1. State arthritis programs lack visibility. Arthritis receives little attention internal or external to the health department. Most arthritis program managers do not experience much interest or receive much oversight from upper management. Overall, arthritis is not a high priority problem in the health department or within chronic disease programs. Solutions:
 - a. CDC needs to increase the visibility of arthritis at NCCDPHP, CoCHP, and with the CDD.
 - b. CDC Arthritis Program needs to explore re-establishing a relationship with Council of State Governments (CSG).
 - c. The Arthritis Council needs to increase the visibility of arthritis as a public health problem and arthritis programs in the state health departments and with CDD leadership, and consider having special sessions at chronic disease meetings.
2. Staff turnover seriously interferes with progress. Since most supervisors of arthritis programs have very little experience with arthritis, new coordinators struggle without adequate direction and mentorship. Solutions:
 - a. CDC should provide technical assistance shortly after new state arthritis program managers are hired. If possible, an experienced state arthritis program manager should be included in the site visit.
 - b. New program managers should be linked with an experienced manager.
 - c. The supervisor of state arthritis program managers should attend the technical assistance site visits.
3. Measurable goals and objectives have not been available. Program direction has changed (i.e., become more specific) over the past five years. States felt that having clear expectations (goals and objectives for which they would be held responsible) would help them set priorities and decrease the number of activities underway. Solutions:
 - a. Complete the current goals/objectives/strategies/actions document.
 - b. Conduct a conference call to further discuss and finalize.
 - c. Standardize technical assistance around the G/O/S/A.
4. Program managers often lacked the tools to develop, maintain and enhance partnerships. Since most of the work of state arthritis programs is to broker/facilitate embedding evidence-based programs in existing delivery systems, skills necessary to work with others are essential. Solutions:
 - a. Highlight need for these skills to supervisors of arthritis program managers.
 - b. Encourage state health departments to train managers in partnership skills.
5. Partnerships have been difficult to develop and maintain. In many places, the partnerships with the Arthritis Foundation Chapters have been especially challenging. There are significant issues around partnerships: 1) Money complicates the relationship. Partners may now expect to get paid for activities they did before CDC/state funding became available. Without partnership co-investment, sustainability of efforts is unlikely. 2) Specific roles for partners are

- often unclear, resulting in unclear or unreasonable expectations and lack of progress. Solutions:
- a. Encourage co-funding activities with partners.
 - b. Clarify roles in all partnerships.
6. Surveillance expectations from CDC have not been clear. Most states wanted more epidemiologic support at the state level, although they could not articulate how this would help them reach their overall program goals. Program announcement language could imply that states should explore other data sources. Solutions: See number 8.
7. States are interested in CDC being more directive when providing program guidance. In several areas, there was different understanding about CDC expectations among the states and between CDC and the states. Solutions: see number 8.
8. Communication has not been adequate. See numbers 6 and 7. Although CDC communicates program direction through the program announcement, technical assistance, at Grantee Meetings, and by email, there is not a common understanding of program direction in all components. Solutions for 6, 7, and 8:
- a. CDC needs to further clarify direction and expectations.
 - b. CDC needs to communicate more clearly around direction and expectations and check for common understanding.
 - c. Technical assistance needs to be standardized.

Component-Specific Findings

Funding

Definition of Success

- CDC funding is used specifically for projects within the scope of the cooperative agreement.
- Funds are balanced between staff support and program implementation.
- Sub-awards have clear deliverables and accountability mechanisms, and are consistently monitored.
- Carry-over amounts are minimal (limited to 10-20% of the total award).

Facilitators

- Availability of federal funding.
 - Without federal funding, state arthritis programs would not exist.

Barriers

- Limited available funding.
- The consolidated cooperative agreement causes problems at both CDC and state levels, particularly around submission of financial status reports and requesting carryover funds.
- CDC delays in processing and approving carryover requests.
- Closely aligned federal and state fiscal years that complicate funding logistics.

Observations

- Higher funding levels are not associated with more evidence-based program activity.
- In-kind support and/or state dollars do not ensure visibility or active health department support of the goals and objectives of Arthritis Program.

Short-term solutions

- Ensure messages and technical assistance from CDC and CDC project officers are consistent.
- Ensure states and CDC project officers are monitoring state sub-awards.

Long-term solutions

- Consider one level of funding for all states in future program announcements rather than having two funding levels for essentially the same scope of work
- Seek to eliminate the need for consolidated grants in the future.
- Move toward tying funding levels to performance.

Program Operations

Definition of Success

- Arthritis Program is appropriately staffed.
- Energy and efforts of staff are focused on activities consistent with the program announcement.

Facilitators

- Appropriate staff with appropriate skills (i.e., interpersonal, organizational, partnership building), and who are hard-working and committed to program goals and objectives.
- Strong senior management support at least two management levels above the program coordinator.
- Stable staff and organization.
- Full time Program Coordinators who operate without competing demands.
- Strong organizational support.

Barriers

- Staff turnover.
- Delays caused by hiring processes.
- Lack of early orientation/technical assistance site visits for new program coordinators.
- Re-organizations in health departments.
- Arthritis viewed as a low priority, competing for leadership and resources.
 - Chronic disease program “clutter” (multiple chronic disease programs) takes attention away from arthritis programs.
 - Insufficient management support resulting in the program being ignored and given permission to “fly under the radar.”
- Consolidated cooperative agreement—The consolidated agreement requires additional layers of coordination and paperwork within the health department requiring additional arthritis program manager’s time.

Observations

- Organizational placement does not appear to be a facilitator or barrier by itself—success is more of a result of the partnership building skills of the program coordinator.

Solutions

- Increase visibility of arthritis at CDC, NACDD, and within state health departments.
- States should provide program coordinators with partnership skill building training.
- Conduct orientation-based site visits within 1-2 months for new program coordinators and invite management to attend.

Surveillance

Definition of Success

- BRFSS used as main source of surveillance data (even better: standard tables used as main source of surveillance data).
- Data products (burden reports/fact sheets/burden section in state plan) are produced in a timely manner and distributed widely.
- Data are used to increase visibility of program to public, health professionals, and policy makers.
- BRFSS management module used.
- Other data sources are not pursued without specific purposes.

Facilitators

- Use of standard tables as the initial data source. If no epidemiologist is available, state can use standard tables for burden report, facts sheets, etc.
- Access to epidemiology expertise to help interpret and use standard table data and develop products. A full time epidemiologist does not appear to be warranted.
- Geo-coding the location of the evidence-based intervention classes to identify underserved areas of the state.

Barriers

- Lack of clarity around the depth and breath of surveillance activities. States need to know how much surveillance data is enough.
- Limited staff resources consumed chasing data for unclear program purposes. More precisely defining the arthritis problem does not get programs to the people that need them.

Having a full-time epidemiologist who then chases data of unclear value to the program.

Observations:

- Surveillance data has high credibility and partners rely on departments of health for sound and timely data.
- States desire more epidemiologic support, with unclear program justification.
- Guidance is needed around how to address co-morbidities and quality of life data.
- Co-morbidity and quality of life data need to be addressed in standard tables.
- States would like more information on the percent of people with various types of arthritis. This is currently not available; state programs were unable to articulate how this would promote programs.
- States want regional and county-level arthritis data, and data about arthritis among children.

Solutions:

- CDC needs to clarify expectations around surveillance.
- CDC should consider expanding surveillance data provided to include data on health-related quality of life, co-morbidities, and children.

Burden Reports/Information

Definition of Success:

- Burden information is available in a timely fashion and are widely accessible
- Burden information is used by arthritis program and other stakeholders to
 - increase program awareness.
 - increase program reach.

Facilitators

- Flexibility in scope and form of data products.
- Access to epidemiologic support.

Barriers

- State review processes delaying dissemination.
- Unclear expectations around form and scope of reports (e.g., large burden reports versus fact sheets).

Observations/Issues

- States felt that the burden reports lend credibility to the arthritis program with partners and the public.
- The standard tables and the footnotes to the tables are frequently used and are valuable.
- Data has opened some doors and has the potential to open others.
- States felt that it was important to do one comprehensive, slick burden report. Subsequent data dissemination could take the form of fact sheets.
- Dissemination is often difficult; multiple channels may be necessary (e.g., web and print).

Solutions

- States should have greater flexibility in the form of reports: the form of the report should meet the state's needs.
- Technical assistance needs to be standardized around burden information.

Coalition / Advisory Group

Definition of Success

- Coalition has a clear purpose that advances mission of program.
- Coalition is action oriented to address arthritis in the state through a variety of partnerships
- Coalition helps develop a state plan and is guided by it.
- Partners (coalition members) provide critical link to organizations and access to populations of interest.
- Coalition members have the capacity and willingness to commit their organizations to take action (i.e., to implement tasks or objectives including those of the state plan).

Facilitators

- Roles of the coalition members are clear and include action to address arthritis.
- Coalition has developed a plan with measurable objectives, timeline, and monitoring activities.
- Coalition ideally reflects the state's population (demographic and geographic representation), includes a balance of public health and clinical expertise
- There is consistent follow-up on planned actions.
- For large groups, a steering committee is used to facilitate progress.
- Group understands and utilizes the public health model.
- Group evolves in both activities and members as the plan moves from development to implementation.

Barriers

- The amount and intensity of staff time to build and maintain group.
- State rules and regulations about advisory committees/coalitions interfere with development and progress.

Solutions

- CDC should provide a clear explanation of the public health model and a way to educate coalition about this.
- Identify and disseminate success stories around coalition building.
- Develop and offer training on maintaining coalitions.

Observations on **building** the coalition

- A professional facilitator helps the coalition coalesce and develop an action plan.
- A supportive and committed Department of Health lends credibility to the efforts.
- The inclusion of health care providers (e.g., physicians, physical therapists, occupational therapists) provides balance and a different perspective.
- People with arthritis should be included to bring the consumer perspective.
- Recognize that most members of the coalition will have little knowledge or understanding about public health; allow enough time to educate members/partners on the public health model.

- Group members should represent organizations with interest in arthritis AND have individual interest and expertise in arthritis, or public health.

Observation on **maintaining** coalition momentum after action plan is developed

- Members need to be involved in the development of agendas.
- Orient new members early: new members may not understand public health or know about the progress to date.
- Frequently monitor progress on whether objectives etc. are met; designate someone to be responsible for tracking objectives, activities, and tasks.
- Acknowledge what members do well (and keep awareness of what they can't do) and recognize their accomplishments.
- Encourage members to take responsibility for a job to help keep them engaged over time.
- Arrange for frequent, consistent communication with members and opportunities for feedback through the use of email, Listservs, and Newsletters.
- Hold working meetings; they are better attended than meetings with presentations only.
- Open membership for groups help to reach a broad audience in the state and keep them informed about arthritis program activities.
- Structure meetings so each participant benefits in some way.
- Work with your Arthritis Foundation partner to gain mutual understanding and facilitate meaningful participation.
- State Aging groups with links to AAAs seem to be very helpful in reaching seniors.
- If the Advisory Group gets too wrapped up in implementation they may lose ability to provide objective advice.

Partnerships

Definition of Success

- Partners are actively involved in expanding the reach and sustainability of evidence-based programs.
- Partners provide access to populations with arthritis.
- Partners create greater awareness of arthritis.

Facilitators

- Partners and Arthritis Programs share or have overlapping visions/missions.
- Partners meet each others' needs to help achieve missions.
- Partners participate with both dollars AND in-kind support.
- Partners have mutually supportive relationship.
- Partners and program share credit for successes.
- Roles for partners are clearly defined; they may overlap but should be complementary.
- Partners are members of each others advisory boards.

Barriers

- Lack of role clarity for activities.
- Changes in arthritis program and partners leadership; staff turnover; leadership instability.
- Lack of interpersonal skills necessary to sustain relationships.
- Limited time, funding and staff to invest in finding and maintaining partner relationships.
- Partners view of the state health department as being in control of all activities.
- States and Arthritis Foundation Chapters have different expectations from the partnership.

Observations

- Successful partnerships are not driven by money alone; there are activities that can be done without funds (i.e. in-kind support for activities).
- Successful states have larger bases of partners and more frequent communication
- Successful partnerships foster sustainability.
- States wish to limit partnerships to those that work.

Solutions

- Clarify parameters of successful partnerships: develop fact sheets.
- Partner with those that have an interest in the arthritis evidence-based interventions.
- Clearly define roles of partners.
- CDC should allow states to limit partnerships to those that are productive.
- Foster sustainability of program efforts through partnership.

State Plans

Definition of Success

- State plans are developed for the state and do not only address the health department role for a public health approach for arthritis.
- State plans are used to provide ongoing program direction that lead to implementation of activities and accountability.
- State plans are inclusive of national (CDC) and state goals, objectives, strategies, and action steps.
- State plans served as a catalyst for bringing partners to the table.

Facilitators/qualities of a good state plan

- Goals of the plan are prioritized and include action steps.
- Plans facilitate the ability of the state arthritis program and state to measure progress.
- Plans promote stakeholder buy-in.
- Plans are targeted toward decision-makers and system wide implementers.
- The intended audience and use of the plan are clear.
- The development of the plan is used to build new partnerships.

Barriers

- The amount of time needed to develop a state plan is large.
- The use of the plan is unclear.
- The partners involved in developing the plan do not understand the purposes of the plan.

Observations

- State plans added credibility and value to state arthritis programs.
- The use of outside facilitators resulted in a speedier process and reduced the amount of time needed from program coordinators.
- States with plans modeled after NAAP, endorsed by the commissioner and/or other high profile level of management do not appear to be associated with more program activity.
- States having difficulty in setting program direction and expanding the reach of evidence-based interventions tended to completely overhaul their existing state plans while more successful states tended to make appropriate revisions of existing plans.

Short-term Options

- Provide technical assistance around state plans regarding format, timelines, and revisions.
- Give states the option of combining the required burden report with the state plan or to create a separate report to ensure maximum flexibility.

Long-term Options

- Require state plans in future program announcements, but encourage the use of complementing implementation plans (how-to guides).
- Plans should be regularly reviewed for relevance and to guide revision.

Interventions – Packaged Programs
Arthritis Foundation Aquatic Program
Arthritis Foundation Exercise Program
Arthritis Foundation Self Help Program

Definition of Success

- Reach of evidence-based interventions increased
 - Interventions were delivered.
 - State program able to track growth in reach.

Facilitators

- Leaders were facility based
 - Agency staff who lead program as part of job, or
 - Volunteers attached to a facility.
- State program invested in staff or partners to support intervention delivery (i.e., regional coordinators, grants to community agencies).
- State program partnered with community agencies who saw program delivery as a means to meet their own mission and serve their clientele.
- State program focused on a limited number of interventions, rather than attempting to implement all of them.

Barriers

- Unclear partner roles; unclear and/or unfulfilled deliverables from grantees or contractors.
- Lack of monitoring or holding grantees/contractors accountable.
- Perception that Arthritis Foundation Self Help Program is too long, training is too long and/or requirement for two leaders is unrealistic.
- Difficulties collecting reach data, and lack of confidence in reach numbers, particularly for PACE and aquatics.
- Competing priorities within the Arthritis Foundation between fund-raising and program delivery.
- Lack of shared commitment between State and Arthritis Foundation to expand the evidence-based interventions.
- Lack of non-Arthritis Foundation licensed interventions. States reported that working with the Arthritis Foundation chapters often hampered implementation efforts.

Solutions

- Clearly define roles.
- Clearly delineate roles and deliverables in contracts and hold contractors/grantees accountable.
- Emphasize embedding programs in systems with access to relevant populations and multiple local partners or delivery points (i.e.; hospitals, health clubs, health plans' Area Health Education Centers (AHECs), University Extension Services.

- Expect to collect reach data from any delivery site that state program has had any involvement with (i.e. direct funding, support for training, marketing) and include this expectation in MOU.
- Consider eliminating aquatics from the list of potential interventions for state program focus (Reasoning: state arthritis programs have small role; and in most areas, program is running near capacity).

Issues to clarify

- Scope of reach numbers to collect—just those for which the health department has some involvement, or total numbers for entire state (AF Programs)?
- Further clarify role of state coordinator re: being trainer and/or leader.

Interventions – Packaged Programs Health Communications

Definition of Success

- Campaign implemented as designed.
- State able to estimate reach/impressions.
- State able to leverage resources (donated ads, pooled airtime).

Facilitators

- Using multiple elements of the campaign.
- Using local community partners as an on the ground implementation force to deliver campaign materials.
- Partnering with community leaders and getting into community with plenty of lead time.
- Supplemental funding.

Barriers

- The amount of time and labor needed to distribute brochures and flyers/
- Difficulty measuring impact (No baseline on awareness; difficulties measuring changes in awareness).

Solutions

- Be more focused: target specific areas or populations.
- Recruit strong community partner and on-the-ground implementation force.
- Collect, at a minimum, impressions and other process data.

Program Evaluation

Definition of Success

- States monitor progress toward program goals/objectives in state plan and program work plans.

Facilitators

- Ability to obtain reach data.
- Evaluation efforts are established during program planning.
- Evaluation efforts are prioritized and are consistent with priorities of program announcement and state program.
- Progress is monitored over time.

Barriers

- Lack of evaluation expertise, time, and other resources.
- Lack of understanding among partners.

Observations

- Some states are measuring impact without having solid reach numbers first.
- Some states are evaluating activities that are low priority and fairly easy to evaluate (i.e. advisory group satisfaction) rather than intervention expansion efforts.
- Struggling states tend to use the required annual report as their primary evaluation tool.
- Successful state evaluation efforts are focused on monitoring reach of evidence-based interventions rather than health outcomes.

Solutions

- Re-iterate the importance of obtaining reach data through partners.
- Establish evaluation priorities.
- Provide guidance and training on evaluation for program coordinators.
- Continue to clarify importance and use of the Impact Tool to capture program reach data.

Awareness and Education

Only observations are given.

Observations:

- Awareness activities were not addressed in the program announcement, therefore success was not defined. In addition, few state programs were doing any evaluation of their awareness activities.
- Most awareness activities were very non-specific; rarely was “awareness of what” defined.
- Rarely were awareness activities linked to achieving program goals.
- State programs who were investing more time or energy in awareness or educational activities spent less time in expanding the reach of evidence-based interventions.
- Health fairs, conferences, and exhibits consumed staff resources/ time and do not appear to add value.

Proposed Indicators of Success:

- Awareness activities are well justified.
 - Target of activity (i.e. awareness of “what”) is clearly defined.
 - Activity is clearly linked to advancing program goals.
- Results were measurable and were measured.

Solutions

- CDC should standardized guidance around awareness and education activities.
- Awareness activities should only be done to expand the reach of evidence-based interventions.
- States should track resource investment in awareness activities.

Policy

Since success was difficult to define in the area, only observations are given.

Observations

- Arthritis advocacy and policy issues are predominately the responsibility of partners (i.e., Arthritis Foundation).
- States have helped raise awareness and obtain Arthritis Month resolutions, but having a resolution is not associated with visibility, leveraged funding, or success.
- Increased national attention is needed.

Short-term Options

- Work with partners to identify policy gaps and advocacy priorities.
- Discuss policy needs and options with the CDC policy group.
- Consider engaging the Council of State Governments.
- Present results of the Comprehensive Site Visit project to Chronic Disease Directors; request that CDD suggest legislative action and help establish policy priorities.

Long-term Options

- Engage the Arthritis Foundation—National Office in discussions on how to influence chapters to be more active in state advocacy activities.
- Engage in national level activities to bring more national attention to arthritis.

Top List for Immediate Technical Assistance

Nominees for the Top Ten or Golden Rules list:

- Partner with those that have an interest in the arthritis evidence-based interventions.
- States may limit partnerships to those that are productive.
- Clearly define roles of partners, define expectations.
- Emphasize embedding programs in systems with access to relevant populations and multiple local partners or delivery points.
- Focus on a limited number of interventions and do a couple well rather than attempting to implement all the interventions.
- For health communication campaigns, recruit strong community partner and on-the-ground implementation force before implementation begins.
- Limit awareness activities to those that lead to expanding reach of evidence-based interventions.
- CDC will try (as travel budget allows) to conduct technical assistance/orientation-based site visits within 1-2 months for new program coordinators and invite management to attend.
- States are allowed to limit surveillance activities to the standard tables and tracking the reach and location of evidence-based intervention programs.
- CDC will expand available surveillance data to include data on health-related quality of life, co-morbidities, and children.
- Burden reports should meet the state's needs and can take the form of a large burden report, fact sheets, or some other mechanism that results in timely and widespread dissemination of data.
- States have the option of combining their burden report with the state plan or to create a separate report to ensure maximum flexibility.

Appendix 1 – Process/Methods

A standard protocol was developed to address overall program status and ten component-specific activities (funding, program operations and staffing, surveillance, advisory group, partnerships, state plan, interventions, program evaluation, public awareness and education, and policy development.). Where possible, facilitators and barriers were identified. The protocol was developed with the input of an Arthritis Council consultant with more than 40 years of state/Federal program experience, AC members and CDC staff. The protocol, consisting of a state preparation checklist, pre-visit assessment and the site visit assessment, was field tested in two states (NY and UT) and revised using feedback from the site visits, UT and NY state arthritis program staff, and CDC. Fifteen two-day site visits were conducted between January 24 and November 10, 2005.

Site visit teams were comprised of the AC, NACDD consultant and CDC representatives. All site visits were facilitated by the AC Consultant, who coordinated the pre-assessment, the site visit teams, ran the meetings and developed the final reports. The other members of the teams were CDC scientists and/or project officers. To maintain objectivity in collecting information, the science consultant and project officers assigned to a particular State Arthritis Program were not permitted to serve on the review team for that State Arthritis Program.

Reports were developed by the AC consultant based on the pre-assessment, the collection of documents provided to the review team at the on-site review, and the on-site discussions. Drafts were shared with other members of the site visit team, revised and then shared with the state arthritis program manager to check for accuracy.

A retreat was held November 30 through December 2, 2005 to review the findings from the 15 site visits, identify major overall themes, define success in the ten cooperative agreement subcomponents, and look for common facilitators and barriers for success or lack thereof. All participants read all of the site visit reports. Two participants were assigned to each component for more intense review. Specifically they worked together to define success for that component (if possible), identify facilitators and barriers, contrast states who appeared to have more success in that component to those who do not, identify any issues for further discussion and make recommendations for next steps. This information was presented to the group for further discussion. Two areas did not lend themselves to defining success (public awareness and policy). Observations are listed for these sections.

Appendix 2 – Pre-assessment and Site Visit Protocols

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Arthritis Council/Chronic Disease Directors

State Arthritis Program Review

On-site Review State Preparation Checklist

This checklist is designed to assist states in gathering materials and information when preparing for the on-site review. You should have this information readily available during the visit as reference documents during the discussion sessions.

Preparation for the visit should not be cumbersome. Please feel free to use existing materials whenever possible rather than creating new documents. For suggested materials, one copy should be available for the review team at the end of the visit.

FUNDING

Suggested Materials

- State Arthritis Program budgets reflecting CDC funding from 1999—2004 (424 forms or budget narratives from applications would be ideal). Budget should reflect the allocation of the total funds by category, number of FTEs, and in-kind support by position or type (epidemiologist, health educator, education materials, etc.)
- Summary of funds available to the State Program by sources other than the CDC Arthritis Program (i.e., other CDC program, other federal agency, state, partners, foundations, private sector, etc.).
- List of entities receiving state arthritis program funding. Total funds paid to the entities each year, purpose of funding, and funding mechanisms used (MOU, contract, IPA).

Discussion Points

- Overall budget issues, lessons learned from implementing various funding mechanisms, and issues that facilitated or created barriers to success related to funding.

PROGRAM OPERATIONS & STAFFING

Suggested Materials

- Organizational chart showing the placement of the State Arthritis Program within the State Health Department.

Discussion Points

- Program's ability to communicate directly with the state Fiscal Office.

- Employee turn-over and/or re-organizational effects.
- How your program interacts with other State Health Department Chronic Disease or Health Promotion Programs.
- Challenges encountered and how they were addressed.

ADVISORY COUNCIL/COALITION

Suggested Materials

- List of Coalition members with workgroups or subcommittees. For coalition members, indicate the partner group (if appropriate) they represent and the length of their involvement.
- Procedure documents or other relevant materials related to Coalition.

Discussion Points

- Organization of the coalition (workgroups, assignments, etc.)

PARTNERSHIPS

Suggested Materials

- List of State Arthritis Program Partners
- Partnership Satisfaction Surveys (questionnaire and results)

Discussion Points

- Partnership interactions and satisfaction survey efforts
- Challenges encountered and how they were addressed

SURVEILLANCE & BURDEN REPORT

Suggested Materials

- Copies of past/present "State Burden of Arthritis Report"
- Fact Sheets or other publications

Discussion Points

- Development, dissemination, and current status of the report.
- How BRFSS data is used to drive program activities and any other uses of BRFSS data.
- Analyses and use of other data sources.

- Evaluation of Usefulness
- Challenges encountered and how they were addressed

STATE PLAN

Suggested Materials

- Copies of state plan(s).

Discussion Points

- Development and dissemination processes used for your state plan.
- Data sources used in developing your state plan
- Usefulness of state plan
- Evaluating usefulness
- Challenges encountered and how they were addressed

INTERVENTIONS/AWARENESS/EDUCATION

Suggested Materials

- “Reach” measures. Measuring “reach” includes establishing mechanisms to determine annual availability and delivery of evidence-based self-management programs (ASHC, PACE, Aquatics). “Availability” measures the number of programs offered and their geographic dispersion. “Delivery” measures the number of programs given and the number of persons with arthritis attending.

Provide the number of state-identified course sites, courses offered, and number of registrants/participants whenever possible.

Provide the number of master trainers, leaders, and trainers your state has trained. For the current year, provide the number of active trainers and leaders.

- Education and/or campaign materials (including, but not limited to CDC's “Physical Activity. The Arthritis Pain Reliever” campaign).

Discussion Points

- Past and present evidence-based interventions you have implemented. Facilitators and barriers to success. Lessons learned since initial funding year.

- Training processes and marketing/recruitment strategies used to implement evidence-based interventions.
- Past and current implementation of CDC's health communications campaign, "Physical Activity. The Arthritis Pain Reliever." Describe strategies used to implement the campaign (number of brochures, number of radio spots and print ads, number of PSAs, etc.). Identify the location(s) of the campaign and impact. Discuss partner involvement.
- Additional interventions, outreach and education efforts, or other awareness strategies
- Professional/allied professional educational activities funded with non-CDC funds.
- Arthritis program Web-site efforts.
- Evaluating usefulness
- Challenges encountered and how they were addressed

PROGRAM EVALUATION

Suggested Materials

- Evaluation tools used, surveys, other evaluation-type materials
- Results of evaluation

Discussion Points

- Program evaluation efforts and methods, if any. (outcome/formative/process)
- Evaluation resources available/used (health department staff, university program, contractor, partner staff, etc.), if any.
- Challenges encountered and how they were addressed.

POLICY DEVELOPMENT

Suggested Materials

- Copies of any policy/legislative briefs ("white papers, " issue papers, etc.) developed by or that effects the State Arthritis Program or its partners.

Discussion Points

- What and how (if any) state policies (legislative or other) have impacted the State Arthritis Program.

- Activities used, and by whom, to promote proposed legislation or policies.
- Challenges encountered and how they are addressed.

Arthritis Council/Chronic Disease Directors

**State Arthritis Program Review
Pre-Assessment**

State Program _____

Completed by: _____ **Date:** _____

This self-assessment is designed to gather basic information about your State Arthritis Program during the 1999—2004 CDC funding years. Where narrative responses are requested, please be brief and concise. The response should serve as an indicator to the state program and the review team of those areas that need to be discussed in detail during the on-site visit. This information will help the review team prepare for the on-site visit, and will help determine the amount of time needed for each component of the review.

I. FUNDING

Please check the years your state has received CDC funding for Arthritis Program activities.

☐ **1999** ☐ **2000** ☐ **2001** ☐ **2002** ☐ **2003** ☐ **2004**

Does your arthritis program receive any state or other funding to supplement federal funding? **Yes** _____ **No** _____

If yes, please specify source, years, and original purpose of the funding.

II. PROGRAM OPERATIONS & STAFFING

How many Program Coordinators has your program had since receiving CDC funding? _____

Briefly list staff changes and why.

Since the original year of funding, has the Arthritis Program been affected by State Health Department re-organization? **Yes** _____ **No** _____

If yes, briefly describe the situation and affect. _____

In addition to the Program Manager, how many staff members comprise the Arthritis Program? _____

Please provide names, titles, length of time with program, and source of funding (state employee, shared employee, university personnel, contract etc. as per examples)

Name or Agency	Title/Role	Length of time with Program	Funding Source (Include In-Kind)	Notes
<i>Mary Green</i>	<i>Prog. Coord.</i>	<i>2 yr.</i>	<i>CDC Grant</i>	
<i>Jane White</i>	<i>Epidemiologist</i>	<i>6 mo.</i>	<i>State</i>	<i>Shared with Chronic Disease</i>
<i>John Brown</i>	<i>Hlth Educator</i>	<i>1 yr</i>	<i>Contract</i>	<i>State University</i>

Has your program encountered challenges related to program operations and/or staffing? **Yes** _____ **No** _____

If yes, briefly describe the situation(s) _____

III. PARTNERSHIPS

List up to five active partners and/or organizations your program is most involved with. Indicate if they are internal or external.

1. _____

2. _____

3. _____

4. _____

5. _____

Does your program conduct a partnership satisfaction survey? **Yes** ____ **No** ____

If yes, list how the findings are used. _____

Has your program encountered challenges related to partnerships?

Yes _____ No _____

If yes, briefly describe the situation(s) _____

IV. Surveillance & Burden Report

Which years have you used core BRFSS data for arthritis program activities?

☐ 1999 ☐ 2000 ☐ 2001 ☐ 2002 ☐ 2003 ☐ 2004

Which years have you purchased additional modules? Please specify which modules you purchased for each year.

☐ 1999 _____

☐ 2000 _____

☐ 2001 _____

☐ 2002 _____

☐ 2003 _____

☐ 2004 _____

List titles and dates of burden/state of arthritis reports published since 1999.

Do you ever use BRFSS data for reports other than the burden document?

Yes _____ **No** _____

If yes, please specify the type of report(s) _____

What other data sources do you analyze?

1. _____

2. _____

3. _____

4. _____

Have you evaluated the use of your burden/state of arthritis report?

Yes _____ **No** _____

Has your program encountered challenges related to surveillance and the development of your burden/state of arthritis report? **Yes** _____ **No** _____

If yes, briefly describe the situation(s) _____

V. STATE PLANS

Do you have a state plan? **Yes** _____ **No** _____

If yes, what year was it originally published? _____

Has it been updated since originally published? **Yes** _____ **No** _____

If being revised, what is the current status of the revision?

In progress _____ Completed _____ Published/Date _____

Is the plan available in **hard copy** _____, **online** _____, or **both** _____?

If online, please specify Web site address _____

Do you find your plan useful for program guidance? **Yes** _____ **No** _____

Have you evaluated the usefulness of your plan? **Yes** _____ **No** _____

Has your program encountered challenges related to state plans? **Yes** ____ **No** ____

If yes, briefly describe the situation(s) _____

VI. INTERVENTIONS/AWARENESS/EDUCATION

Check the years that your program (contractor/partner) has implemented the following evidence-based interventions.

PACE

☐ 1999 ☐ 2000 ☐ 2001 ☐ 2002 ☐ 2003 ☐ 2004

ASHC -English

☐ 1999 ☐ 2000 ☐ 2001 ☐ 2002 ☐ 2003 ☐ 2004

ASHC -Spanish

☐ 1999 ☐ 2000 ☐ 2001 ☐ 2002 ☐ 2003 ☐ 2004

AF Aquatics

☐ 1999 ☐ 2000 ☐ 2001 ☐ 2002 ☐ 2003 ☐ 2004

CDC's Health Communications Campaign "Physical Activity. The Arthritis Pain Reliever."

Please check the years implemented and materials used.

☐ 2002: ☐ **Print Ads** ☐ **Paid Radio Spots** ☐ **PSA Radio Spots**
 ☐ **Brochures/Holders** ☐ **Posters**

☐ 2003: ☐ **Print Ads** ☐ **Paid Radio Spots** ☐ **PSA Radio Spots**
 ☐ **Brochures/Holders** ☐ **Posters**

☐ 2004: ☐ **Print Ads** ☐ **Paid Radio Spots** ☐ **PSA Radio Spots**
 ☐ **Brochures/Holders** ☐ **Posters**

List any other interventions or educational/awareness programs and/or activities you have implemented and the year. (i.e., conferences, summits, professional education).

Intervention	Year
1. _____	_____
2. _____	_____
3. _____	_____
4. _____	_____

Has your program encountered challenges related to interventions, awareness, or education? Yes _____ No _____

If yes, briefly describe the situation(s) _____

VII. PROGRAM EVALUATION

Which aspects of your program have been evaluated? Please check.

- ☐ Interventions ☐ Partnerships ☐ Program Operations
☐ Public Awareness/Education ☐ State Plan ☐ Data Report

Other _____

Has your program encountered challenges related to program evaluation?

Yes _____ No _____

If yes, briefly describe the situation(s) _____

VIII. POLICY DEVELOPMENT

Has your state developed any policy/legislative documents that affect the arthritis program, or is there any state legislative language related to arthritis prevention or control? Yes _____ No _____

Who initiates these activities? Internal partner _____

External partners _____ State funded program _____

Do these initiatives include funding? **Yes** _____ **No** _____

List any activities that are held in your state (by the program or partners) to promote policy or legislative activities?

Has your program encountered challenges related to policy development?

Yes _____ No _____

If yes, briefly describe the situation(s) _____

State Arthritis Program Review
Part B: On-Site Review Team Guidance

State Program _____ **Date** _____

Review Team _____

This is not a technical assistance site visit. Therefore, we are not here to review specify programmatic or scientific issues and will not be making recommendations to the state program.

This review is a joint project of the Arthritis Council and CDC's Arthritis Program. We are here to gather information on the successes and challenges experienced by the _____ Arthritis Program. We desire to extract lessons learned from _____ and the other states and to identify common facilitators and barriers to success.

The comprehensive reviews are designed to benefit State-based Arthritis Programs, the Arthritis Council, and CDC by assisting in the:

- Identification of fundamental elements of successful State-based Arthritis Programs. Information gathered will also be valuable for establishing program credibility with state and federal policy makers, partners, and other key stakeholders;
- Identification of program gaps, factors that influence success, and barriers that impede progress; and
- Gathering of accountability information to shape the future direction and roles of state and national programs.
What have we accomplished? Have our accomplishments lessened the burden of arthritis? What have been the facilitators and barriers to these accomplishments? What are the challenges for the future - near term and long term?

We will be providing you with a list of our observations. The observations from the 16 site visits will be complied into a composite report that hopefully will describe a model state arthritis program at the A and B levels and will serve as guidance for future state programs.

I. FUNDING

If you had additional funds, where would you spend it?

How many years have you had to request to carry forward un-obligated funds?

What situations caused you to have carryover?

What is the State Program's award process for funding sub-projects?

Have you received funding from sources other than CDC? If so, identify the source and purpose of the funding.

Who else in your State is investing in arthritis activities, and how do they collaborate with the State Arthritis Program?

II. PROGRAM OPERATIONS

For this section on program operations, consider the challenges your program has faced in carrying out activities of the program announcement

What is the working relationship between the Program Manager and the PI?

On a scale of 1-5, where 1 = total support, and 5 = no buy-in or support, how much buy in or support does the Arthritis Program have from SHD senior management and the SHO? Explain your rating.

Is the organizational placement of the State Arthritis Program an advantage or disadvantage to the program? Explain your response.

What is the relationship between the Program Manager and the SHD fiscal office?

What is the congruency of state and federal fiscal year and grant budget periods? Conflicts?

Does the Program Manager have competing responsibilities within the SHD?

III. SURVEILLANCE

BRFSS

How do you identify which optional modules should be purchased?

Have you done additional analyses of BRFSS data? If so, what data did you analyze, and who did the analyses?

How is the surveillance data used

How useful are the standard tables to your program?

How do you use the CDC Arthritis Wheels?

OTHER DATA SOURCES

What other data sources have been used by your State Program?

What questions were you trying to answer with this data, and how has the information been used?

Who analyzes these data?

Does the State Burden Report add value to your State arthritis activities, if so, how?

Where are the gaps in our PH surveillance systems as they relate to arthritis? How would you use that info if we had it?

IV. ADVISORY GROUP

How is your advisory group structured and what do you refer to it as (Council, Coalition, etc.)?

How many members are on your group, and what is the average participation at a meeting?

How does your group meet (on-site, telephone, email, etc.) and at what frequency? How has this changed over time?

Who chairs the group? Who takes minutes?

Does the group serve primarily as advisors to the health department, or do they assume responsibility for specific activities in the state arthritis plan.

What happens at meetings? How are they organized? (Is there open discussion? Committee or workgroup reports? Speaker presentations?)

How did you identify members of your group representatives? Describe the geographic, organizational, and ethnic diversity of your Council/Coalition.

Describe the program resources (funds, staff time, travel, etc.) required to operate your Council.

V. PARTNERSHIPS

ARTHRITIS FOUNDATION CHAPTER(S)

Does the AF Chapter have a clearly defined role in the State Arthritis Program?

How did you go about determining those roles and reconciling different needs?

How well does the Chapter understand the public health approach to arthritis?

How is data shared with the Chapter

Has the Chapter taken on an advocacy role for your State Program?

Is your State Health Department Arthritis Program a collaborating partner in AF and other partner projects? What is your role in those projects?

Have there been conflicts between the State Program and the Chapter? If so, how was it, or is it being, resolved?

Partner 2

What does this partner(s) bring to the arthritis program?

Partner 3

What does this partner(s) bring to the arthritis program?

Partner 4

What does this partner(s) bring to the arthritis program?

Partner 5

What does this partner(s) bring to the arthritis program?

PARTNERSHIP SUMMARY QUESTIONS

What makes a partnership successful and what are the major challenges?

Describe the State arthritis Program's relationship with other SHD programs, other state agency programs

What partnerships would you consider to be the most valuable or most productive?

Which partnerships were not successful and why not?

Who else do you need or want to seek partnership with?

VI. STATE PLAN

What partners were involved in developing your State Plan?

How were priorities established?

How was the State Plan disseminated? To whom?

Who are the target audiences for your State Plan?

How has your State Plan been used since its approval?

What are your plans for updating or revising the state plan?

Has the State Plan added value to your State arthritis activities?

VII. INTERVENTIONS

(If not implementing all of the interventions)

What was the rationale for selecting the interventions that you did choose to implement?

EVIDENCE-BASED INTERVENTION PROGRAMS

ASHC

What role does the health department play in the delivery of ASHC?

What have been your most successful strategies to recruit

Sites?

Trainers?

Leaders?

Participants?

What strategies have not worked?

**How many times has ASHC been offered?
(If you cannot provide numbers, what are the barriers to determining “reach?”)**

How many participants enrolled in ASHC (for whatever time frame you have these numbers)?

What kind of quality control/monitoring have you done surrounding ASHC?

Has money been spent by the HD for ASHC? If so, how has that money been spent (i.e. trainings, leader honorariums, books, etc.)

**How has the implementation of ASHC been evaluated, and what results have you obtained?
What were the results?**

Do you plan to sustain these interventions? If so, how do you plan to go about doing that?

PACE

What role does the health department play in the delivery of PACE?

What have been your most successful strategies to recruit

Sites?

Trainers?

Leaders?

Participants?

What strategies have not worked?

**How many times has PACE been offered?
(If you cannot provide numbers, what are the barriers to determining “reach?”)**

How many participants enrolled in PACE (for whatever time frame you have these numbers)?

What kind of quality control/monitoring have you done surrounding PACE?

Has money been spent by the HD for PACE? If so, how has that money been spent (i.e. trainings, leader honorariums, books, etc.)

How has the implementation of PACE been evaluated, and what results have you obtained? What were the results?

Do you plan to sustain these interventions? If so, how do you plan to go about doing that?

Aquatics

What role does the health department play in the delivery of Aquatics?

What have been your most successful strategies to recruit

Sites?

Trainers?

Leaders?

Participants?

What strategies have not worked?

How many times has Aquatics been offered? (If you cannot provide numbers, what are the barriers to determining “reach?”)

How many participants enrolled in Aquatics (for whatever time frame you have these numbers)?

What kind of quality control/monitoring have you done surrounding Aquatics?

**Has money been spent by the HD for Aquatics?
If so, how has that money been spent (i.e. trainings, leader honorariums, books, etc.)**

**How has the implementation of Aquatics been evaluated, and what results have you obtained?
What were the results?**

Do you plan to sustain these interventions? If so, how do you plan to go about doing that?

HEALTH COMMUNICATIONS

**When and where have you implemented
“Physical Activity. The Arthritis Pain Reliever.” ?**

What components of the campaign have you implemented?

What are the barriers to implementing the campaign as designed?

What were the health department roles in implementing the campaign?

What role did partners play in implementing the campaign (who, and what did they do?)

How much did you spend implementing the campaign? What did you spend it on?

What percentage of the radio ads and print placement ads were paid?

Did you pay for the placement of print advertising?

How did you monitor the results of your campaign implementation?

NON-EVIDENCE-BASED INTERVENTIONS

(Intervention Name)

OTHER PHYSICAL ACTIVITY PROGRAMS:

Why did you choose this intervention?

How did you determine to implement it?

What does it cost to implement it?

How many participants did you reach?

**How do you monitor and evaluate the program?
Do you plan to sustain it or would you implement
it again?**

VIII. PUBLIC AWARENESS/EDUCATION

(Program)

Why did you choose this activity?

How did you determine to implement it?

What does it cost to implement it?

How many people did you reach?

How do you monitor and evaluate it?

**Do you plan to sustain it or would you implement
it again?**

PROFESSIONAL EDUCATION

Why did you choose this activity?

How did you determine to implement it?

What does it cost to implement it?

How many providers did you reach?

How do you monitor and evaluate it?

Do you plan to sustain it or would you implement it again?

OTHERS

Why did you choose this activity?

How did you determine to implement it?

What does it cost to implement it?

Who (and how many) did you reach?

How do you monitor and evaluate it?

Do you plan to sustain it or would you implement it again?

Does the State Program or its partners offer CE credits for professional/allied professional training courses?

WEBSITE

Approximately how many hits does your Website get a year? (Is it increasing or decreasing)?

What type of material do you have on your website, and where does it come from?

Who reviews medical/clinical information for accuracy?

What form of evaluation do you use for your Website?

What is the cost to the program for maintaining a Website?

IX. PROGRAM EVALUATION

How does the State Program measure the impact of the Overall program (rather than just specific interventions)?

Beyond reporting to CDC, how does the State Program use progress reports?

X. POLICY DEVELOPMENT

What questions from your legislature/policy staff have required responses from the AP?

Has the AP or partners been proactive on policy issues?

What were the issues?

Does your State have any legislation that has an impact on arthritis program activities? If so, what does it mandate?

XI. CLOSURE QUESTIONS

What five things do you now have that you would not have had without the arthritis monies?

In summary, what makes your program successful?

What interferes with success?

What is most in your way?

What can the Arthritis Council or CDC do to help you be more successful?

Appendix 3 – Participating states and review schedule

New York	January 24-25, 2005
Utah	February 2-3, 2005
Tennessee	March 11-12, 2005
Ohio	April 11-12, 2005
California	April 14-15, 2005
Oklahoma	May 16-17, 2005
Arkansas	May 19-20, 2005
Minnesota	June 6-7, 2005
Missouri	June 9-10, 2005
Illinois	June 13-14, 2005
Indiana	June 16-17, 2005
Florida	July 18-19, 2005
Alabama	July 21-22, 2005
Georgia	August 29-30, 2005
Connecticut	November 10, 2005

Appendix 4 – Retreat Participants

Arthritis Council, NACDD

Larry Burt, Consultant for the National Association of Chronic Disease Directors
Independence, Kansas

Heather Murphy
Chair, Arthritis Council
FL Department of Health, Bureau of Chronic Disease Prevention and Health Promotion
Arthritis Prevention and Education Program Administrator

Mari T. Brick
Chair-Elect, Arthritis Council
New York State Department of Health
Arthritis Program Manager

Centers for Disease Control and Prevention, Arthritis Program, Atlanta, Georgia

Julie Bolen, Epidemiologist
Teresa Brady, Senior Behavioral Scientist
Lee Ann Ramsey, Project Officer
Joe Sniezek, Chief